

# The development and efficiency of the support group in Taiwan MND Association

Chin-Mei Lin, Hui-Fang Tsai,  
Shan-Hwa Liang, Yun-Ju Lin

# Background of study

- Difficulties facing the diagnosis of ALS/ MND
- Meet with other patients or families
- Peer support group since 2005

# The purpose of study

- To understand the experience and meaning of attending the group
- To adjust the support group service in the future

# Development of the group (1)

- Start from 2005
  - a counselor as the leader and a social worker as the co-leader
  - once a week for eight sessions
  - Patient and family member in same group
  - Patients in different stages of illness
  - 6 to 8 people in one session

# Development of the group (2)

- 2010
  - 2 hours once a month for 8 months in a row
- 2013
  - New members and old members in different groups

# Methods- Data collection

- 5 patients and 4 family members continuously attended the support group more than one year
- semi-structured interviews
- single interview, average time of 1.5 to 2 hours

# Methods- Data analysis

- interviews were recorded and then type-written precisely
- open coding → grouped into main concepts → axial coding → developed into categories

# Results and Discussion (1)

- **Motivation of continuously attending the peer support group**
  - To meet with other patients and learn more about the disease
  - To share and learn how to cope with the disease better.
  - Value the time spent with other patients.
  - To help and encourage other patients particularly the new diagnosed patients so they can adjust quicker



# Results and Discussion (2)

- **Gains/ Benefits**

- Information exchange
- Feel encouraged, comforted, cared and more confident
- Have chances to express feelings
- Something to look forward to
- Improve the communication within family
- Support each other

# Results and Discussion (3)

- **Process of psychological adjustment**
  - nervous, depressed and sad
  - seek information, try to overcome then plan for the future
  - Accept (religion helps to let go)
  - Living with the disease peacefully
  - Devote to help others (new members and the public)

# Results and Discussion (4)

- **Suggestions for the group**
  - continue held the support group
  - Find out reasons of stop attending the group
  - new members and old members in the same group, new members get more help

# Conclusions

- With the facilitation of the professional leader, the group has a sense of camaraderie; members share practical issues in a very meaningful way
- The group helped members developing coping strategies

- help the new patients and their families to know the disease better and adjust better. Meanwhile, the old members feel encouraged by helping others
- social worker should check up on members stop attending the group and continue follow up
- Future research
  - Reasons for stop attending the group
  - Meaning for different stage illness

Yun-Ju(Julia) Lin

Secretary General, Taiwan MND Association

Email: [lin@mnda.org.tw](mailto:lin@mnda.org.tw)

**THANKS FOR LISTENING!**